

National Center for Complementary and Alternative Medicine

Strategic Planning: Mandate and Mission

Summary of Public Comments

Since its creation as an independent Center in 1998, the National Center for Complementary and Alternative Medicine (NCCAM) has twice developed strategic plans (2000-2004; 2005-2009) to help guide the implementation of its legislative mandate. As NCCAM embarks on its third strategic planning process, it is important to 1) assess whether and how recent developments in science, medicine, and health care have affected the Center's strategic approaches to its mission and legislative mandate, and 2) identify opportunities that will maximize the impact of its activities on the public and the public good.

To aid this process, NCCAM posted a white paper on its website in September 2009 and invited public comment regarding its mandate and mission. This paper provides a summary report of the public comments that were received. It does not necessarily represent the views or conclusions of NCCAM, which are still in the process of being developed, about either the white paper or the comments received.

Issues of Interest

The public was asked to provide feedback on three specific issues regarding NCCAM's mandate and mission:

Issue 1: Major features of the current CAM research landscape that are important in considering future strategic directions for NCCAM and the field of CAM research in general.

Issue 2: Particular needs and opportunities of importance to NCCAM's efforts in research capacity building.

Issue 3: Opportunities, obstacles, and NCCAM's future role in supporting research on approaches to improved states of general health and well-being.

Respondent Demographics

To address these issues of interest, 163 respondents provided input. Of the total respondents, 161 provided optional demographic information. The majority self-identified as CAM users (37%) and/or CAM practitioners (37%). Other categories included other health care practitioners (14%), researchers (13%), students (9%), and "other" (17%). Forty-two respondents (26%) identified themselves with more than one category.

Methods

NCCAM posted the document on-line for six weeks and solicited comments from the general public via Federal Register, NCCAM Update, the NCCAM website (and RSS feed), and Twitter, as well as targeted emails to several hundred stakeholders (e.g., funded investigators, NCCAM Update subscribers, third party organizations). NCCAM staff reviewed all responses that were provided. Because respondents did not generally structure their feedback strictly according to the three issues, for this report comments were sorted into topics broadly relevant to the mandate and mission of NCCAM. In the following compilation, closely related comments have been pooled together and are summarized as themes.

Conduct of Research

There were numerous comments regarding the importance of ensuring the use of real-world settings and scientific rigor in CAM research. They have been grouped into the following themes:

- Effort must be made to evaluate CAM as it is actually practiced. Clinical trials should measure the effectiveness of multiple, personalized, holistic interventions in real-world settings.
- Using biomarkers as surrogate endpoints for disease and wellness could increase CAM research capacity by providing the foundation for shorter and more cost-effective intervention studies.
- Studies should always involve practitioners of the CAM modalities being studied. It would help to understand more about patient preferences and decision making, particularly as they relate to patient-provider communication and partnerships.
- NCCAM research coincides with the CAM model of patient-centered care, functional medicine, and social research. Leveraging study designs and results from the international arena could provide some evidence as to what therapies have lasted, grown, and are endorsed by other governments and health agencies.
- NCCAM should continue its emphasis on proper characterization of test material used in clinical trials, which assists with reproducibility of results.
- NCCAM should continue to conduct high-quality research according to proven methodologies and standards:
 - Eliminate conflicts of interest
 - Adhere to rigorous research protocols
 - Critically analyze results
 - Convey data and findings to the public in a clear, objective way.
- NCCAM should ensure it is using the same research standards as are used across NIH. The Center must determine how to design scientifically rigorous studies that take into account how CAM is used in real-world settings.

Approach to Research

Several comments were made with regard to NCCAM's overall approach to CAM research. Themes included the following:

- NCCAM research should use a whole systems approach that coincides with the primary areas of research as outlined in the strategic plan.
- The research strategy should combine allopathic, environmental, and functional or integrative medicine.
- Rather than focusing research on finding cures, NCCAM should explore what causes health and prevents illness.
- NCCAM should focus less on the conventional medical model of treating specific diseases and should take a whole-person approach to the optimization of health and wellness. With more emphasis on healthy lifestyle choices, researchers could then study how these choices affect sick-days at work, crime, violence, and other negative aspects of society.
- NCCAM should determine the value of CAM therapies through social research studies, which explore why people choose CAM, what they have tried, and what has been effective or ineffective.
- Priority should be given to modalities that hold the most promise to contribute to the public good. Research efforts should be directed toward both protecting the public from fraudulent information, as well as exploring modalities that are widely used but have not been heavily studied.
- A few responses stated that since it is difficult to quantify states of health and well-being, which are subjective conditions, NCCAM might explore emerging measurements of health status such as omics.
- Two respondents recommended long-term longitudinal research studies on CAM

Collaboration

Comments focused on the utility of NCCAM collaborations with CAM practitioners, international scientists, specialists from a variety of disciplines, and other NIH Institutes and Centers. Themes included the following:

- NCCAM should continue to collaborate with other organizations to leverage research funding. The Center should work with its historic research partners to advance comparative effectiveness research funded under the American Recovery and Reinvestment Act (ARRA).
- NCCAM should work with CAM practitioners from around the world and with specialists from a variety of disciplines, including anthropologists, naturopaths, physicists, chemists, and biologists.

- NCCAM should continue to work with other NIH Institutes and Centers and should expose NIH residents, fellows, and other trainees to good CAM research.
- NCCAM's Trans-Agency CAM Coordinating Committee could be more fully utilized to enhance collaboration among NIH IC's and other Federal agencies to educate and build capacity.
- There should be continued collaboration with the Agency for Healthcare Research and Quality (AHRQ) to develop funding opportunities targeted for practice-based research networks to answer the critical questions of application in actual practice.
- NCCAM should continue to build networks of multidisciplinary research. The Center should educate medical and nursing students about ways to work with CAM providers and should offer incentives for allopathic practitioners to learn about CAM.
- NCCAM researchers should consider opportunities to partner with researchers in Europe and Asia.

Major Obstacles

Various respondents identified several obstacles to CAM research, including the following:

- Views by the public and health care providers, including strongly held beliefs for or against CAM practices in the absence of a solid research base.
- Economic Issues, including funding limitations, independence from interest groups, and lack of health insurance coverage for CAM practices.
- Research design challenges (e.g. individuality of CAM treatment, real-world modeling).
- Influence of the pharmaceutical industry.

Opportunities

Numerous opportunities for increasing NCCAM's reach and effectiveness were identified.

Education and Training:

For researchers:

- Workshops to teach CAM providers how to conduct research.
- Online courses/tutorials in how to access and understand research studies.
- Grant-writing courses for CAM practitioners.
- Research and grant-writing workshops on research designs and methods.

For Public:

- NCCAM should position itself as a household information source, through the use of technology.

- It should see opportunities to raise public awareness of NCCAM and resources at health and fitness expos and trade association meetings and should provide resources at retail outlets where CAM products are sold.

For Staff:

- NCCAM must ensure its staff is well-informed of the existing CAM research by credible research scientists.
- Staff should remain open and objective when learning from CAM practitioners and educators.

For Students:

- NCCAM should increase public awareness of its research by reaching out to CAM schools and physician groups.
- NCCAM should support increased research fellowships and new investigator awards.
- NCCAM should explore ways to support researchers in traditional academic institutions who are willing to mentor students who want to study CAM and integrative medicine.
- NCCAM should work with medical research centers with programs in integrative medicine to develop research training programs that are open to non-allopathic physicians and emphasize research methodology applicable to CAM.
- NCCAM should facilitate ways in which physicians and fully trained and licensed CAM practitioners can work in synchronicity.

Data Collection and Management:

- Given that CAM practice is very individualized, it would be useful to develop a case registry with a well-defined validation procedure.
- NCCAM should also develop medical informatics resources to help acquire practice-based evidence from CAM practitioners.
- There is a need for an efficient way to collect multi-center data to support research in the areas of effectiveness, cost-effectiveness, and comparative effectiveness of CAM therapies and approaches.
- NCCAM should serve as a clearinghouse for individuals with new and innovative ideas to help them translate hypotheses into rigorous studies.
- NCCAM should explore funding for an evidence-based and systematic process to synthesize and review the scientific literature.

Organization and Infrastructure:

- NCCAM's advisory council should include more CAM and integrative health researchers and practitioners to ensure the council's awareness of current trends, thinking, and routine experience within the CAM community and among patients and consumers.
- There should be a more effective way for CAM practitioners to provide feedback and offer opinions and to keep NCCAM apprised of what is going on in the field. To this end, NCCAM could form an assembly of representatives from each modality, which could assist with disseminating data to stakeholders.
- The Center should partner with other NIH IC's, the extramural community, and other Federal agencies to develop a framework for identifying research priorities and determining the most appropriate research methods, tools, and strategies.
- Study proposals should be scored based on cost-benefit analysis and gaps in research.

Other Comments

- Many respondents suggested particular diseases, conditions, or CAM modalities as specific topics meriting research. A large number of homeopathic practitioners suggested that NCCAM place more emphasis on studying homeopathy by consulting with leaders in the field to design trials and identify areas of research promise.
- There were a few responses regarding rephrasing the NCCAM vision statement and renaming NCCAM to include integrative medicine rather than "alternative" medicine.
- While most of the responses received were in support of NCCAM's mandate and mission, one respondent felt that NCCAM should be eliminated.
- One respondent felt that most CAM treatments are fraudulent scams and that there is a pressing need for NCCAM to protect the public.